



Addressing the Costs of Caregiving

Policy Solutions for Caregiver Financial Distress in Ontario

Prepared for the Ontario Caregiver Coalition
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ABOUT THE ONTARIO CAREGIVER COALITION

The Ontario Caregiver Coalition (OCC) is the voice of caregivers in Ontario. We advocate for recognition and support for the family, friends, and neighbours whose unpaid care is the hidden backbone of Ontario’s health system. Our members include both caregivers from across Ontario and organizations that support them. For more information about the OCC and our work, please see our website at www.ontariocaregivercoalition.ca, or follow us on social media.



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INTRODUCTION

In the wake of the Covid-19 pandemic, there has been increased attention to what is sometimes referred to as the “care economy”, with the growing understanding that care is fundamental to a healthy economy and a healthy society.¹ It is becoming more common these days for policy-makers to acknowledge how vital unpaid caregivers are, not only to supporting their loved ones to lead good lives, but also to sustaining our overstretched health, long-term care and social services. Some important steps have been taken to recognize and support family, friends and neighbours who provide 70% of all home care in Canada.² For example, since 2018 the Ontario Ministry of Health has supported the Ontario Caregiver Organization as a single point of access for information about available supports and services.³

However, about one-third of all unpaid caregivers* report unmet needs for supports. The most common unmet need for caregivers is for financial supports.⁴ For the most part, Ontario families and friends are currently left to manage the costs of caring largely on their own. The rapid cost of living increases in recent years have created additional challenges. Heightened expenses for transportation, food, and other basic necessities have left many families in financial crisis. Additionally, the home and community care sector is under intense pressure, due in part to a health human resources crisis that sees approximately 13% of all frontline positions in this sector vacant. Providers are having to cut services or increase waitlists for those needing care.⁵ This also creates additional strains for caregivers as they struggle to fill the gap.

Caregiver financial distress has long-term effects on the health, wellbeing and financial security of caregivers. It impacts their ability to provide high quality care for those they love. As well, financial pressures can contribute to the collapse of caregiving arrangements, leading to repeated admissions to acute care, or to premature or avoidable institutionalization, putting additional strain on our overburdened health, long-term care and social services systems. Caregivers who must reduce their labour force commitments because of their caregiving responsibilities add to the growing labour shortages across the province.

We are at an opportune moment to finally address caregiver financial distress.

*“The end up cost I estimate would be in excess of \$1,000,000 that went to augment [my wife’s] care. The last year alone I spent over \$150,000 for the extra care that was necessary during her final year of life.” (Caregiver)**

* The Ontario Caregiver Coalition defines “caregivers” as follows: “Caregivers are people of all ages who provide essential and often ongoing personal, financial, social, psychological, emotional and physical support, assistance and care, for family members and friends in need of support due to frailty, physical/mental illness, degenerative disease, physical/cognitive/mental disability, addictions or end of life. Caregivers may be spouses, parents, siblings, children and youth, extended family members, friends, neighbours, or the family people choose.

WHAT IS CAREGIVER FINANCIAL DISTRESS?

Caregiver financial distress occurs when the costs associated with caregiving place a significant financial burden on the caregiver, creating economic hardship and additional stress.

Caregiver financial distress is much more common than is generally assumed. The Ontario Caregiver Coalition (OCC) regularly hears from members who are in significant financial difficulties as a result of their caregiving responsibilities, including those who must take out new mortgages or run up lines of credit as result of their caregiving.

WHAT DO WE KNOW ABOUT THE EXTENT OF CAREGIVER FINANCIAL DISTRESS?

- More than half of senior caregivers report needing financial assistance to support their caregiving responsibilities (2018 *General Social Survey on Caregiving and Care Receiving*)
- The COVID-19 pandemic has exacerbated the financial pressures of caregiving. In 2018, 22% of Ontario caregivers reported experiencing financial hardships. By 2020, this number had risen to 45%. (*Spotlight Report 2021: Ontario Caregiver Organization*)
- In 2020, 20% of Ontario caregivers took out a loan or line of credit to help pay for their caregiving expenses (*Spotlight Report 2021: Ontario Caregiver Organization*)
- Of the 30% of caregivers who indicate a desire for additional supports, 68% indicated a need for some type of government financial support, such as a tax credit or other government assistance (2018 *General Social Survey on Caregiving and Care Receiving*)

Given that about 4 million Ontarians are unpaid family caregivers,⁶ caregiving may be a significant and under-recognized contributor to low-income and financial distress in this province.

WHY DO CAREGIVERS EXPERIENCE FINANCIAL DISTRESS?

“I wasn't able to work full time because some of our caregivers or the agencies weren't reliable. And then my sister and I would be juggling taking turns. If they weren't able to cover someone, or if the caregivers were late, who would stay with my parents to make sure that there's somebody there with them before going to work? So I never felt like I could commit to working really for a bit, and that was hard financially.” (Caregiver)

The financial stressors of caregiving come as a surprise to many caregivers. Those who are not yet caregivers can imagine the emotional and mental distress, the time pressures, perhaps even the navigational difficulties, but many caregivers report that they were unaware of the numerous expenses not covered by our health and social systems and were thus unprepared for the financial impact of caregiving. Financial pressures are the result of:

Extensive out of pocket costs: Canadians assume that with our public health system, the costs of caregiving will be minimal. However, inadequate levels of home and community care services leave many families paying for necessary additional supports from private providers, which can be a heavy cost to the caregiver. There may be costs for medications or associated health services, particularly for those with limited or no access to employer-sponsored health benefits. As well, many families end up with significant costs for travel, transportation and accommodation, for transporting loved ones to treatment or for visiting loved ones who are placed in settings outside their home community. Families may find it necessary to undertake significant home renovations to provide an accessible and safe environment for their loved ones. The average Canadian caregiver reports spending \$5 800 per year in caregiving related expenses.⁷

Reduced workforce participation: Caregiving can involve very significant time commitments that clash with employment commitments. According to a 2020 report on caregiving from The Change Foundation, approximately 75% of caregivers juggle work and caregiving. Of these caregivers, in a 12 month period, 30% were late for work or had to leave early, 29% missed an average of 6 days work due to caregiving and 1% had to leave their employment as a result of caregiving responsibilities.⁸ Balancing caregiving with employment can be a high-wire act: a recent report by the Ontario Caregiver Organization found that more than 30 percent of caregivers were either worried about losing their job or considering leaving it because of their caregiving responsibilities.⁹ As a result, caregivers may reduce their labour force participation, or step out of the labour force entirely. It is estimated that 45% of caregivers who are employed experience economic impacts from their efforts to balance caregiver, work and other responsibilities.¹⁰

It is important to keep in mind that these reductions in labour market participation have long-term as well as short-term costs. Work can provide many benefits to caregivers in addition to economic security, including social support and respite.¹¹ When a caregiver refuses a promotion or transfer, reduces work hours, or takes a leave from employment, career trajectories are altered, with a long-term impact on earnings. Reduced payments into employer or government pensions will shape financial security into old

age. And when caregivers move to part-time hours or step out of the workforce entirely, they may lose access to health benefits, in this way further driving up their costs.

WHAT GOVERNMENT SUPPORTS ARE AVAILABLE FOR ONTARIO CAREGIVERS EXPERIENCING FINANCIAL DISTRESS?

“This is where I get emotional, because [my parents] have worked really hard their entire life. They're honest, Canadian citizens who've contributed to their respective employers, who have contributed to the Canadian economy and in this time of dire need, there aren't any grants, subsidies, rebates and that kind of a thing... There are minimal, minimal supports and resources and tax credits available, but it does not outweigh what you pay out.”
(Caregiver)

Financial supports for caregivers are very limited, particularly in Ontario. Nor are existing benefits easily accessible to caregivers.

Compassionate Care Benefits (Employment Insurance): The federal government provides *Compassionate Care Benefits* under the Employment Insurance Program, but these are available only to EI eligible employees who must be away from work temporarily to care for a family member who either faces a significant risk of death within 26 weeks or is dealing with a critical illness or injury that puts their life at risk.¹² Very few caregiving situations fall within these bounds.

Tax Credits: There are several tax credits that may somewhat offset expenses related to care. However, the tax credit landscape is complex.

The federal government provides several tax credits, including the *Disability Tax Credit*, the *Canada Caregiver Credit*, a *Medical Expenses Tax Credit* and a *Home Accessibility Tax Credit*.

The Ontario government provides, in addition to these credits, its own *Caregiver Amount*, the *Ontario Medical Expenses Tax Credit*, the *Ontario Disability Tax Credit*, the *Healthy Homes Renovation Tax Credit* and a newer *Senior Care at Home Tax Credit*.

Some of these tax credits are directed to the care recipient, but may have ancillary benefits for caregivers. Others, like the federal *Disability Tax Credit*, can be transferred from the care recipient to the caregiver in some circumstances.

This landscape creates a complex patchwork of credits for caregivers to understand and access.

It should be noted that all of these tax credits are small in scale. Most are non-refundable, meaning that they have limited or no utility for those who owe little or nothing in the way of taxes.

Some, like the federal *Disability Tax Credit*, have complex eligibility and application requirements, so that taxpayers who may benefit may be deterred from applying for them. Eligibility criteria may restrict

the utility of the credits: for example, it has been pointed out that the *Canada Caregiver Credit* requires that the care recipient have an income below \$24,604 in order for the caregiver to benefit: this is quite a low income.

Caregivers who are eligible are often not aware of the existence of these credits, or may not understand the complex requirements. It is thus not surprising that, for example, only 8% of caregivers report receiving the Canada Caregiver Credit.¹³

WHY DOES CAREGIVER FINANCIAL DISTRESS MATTER?

“There is a financial struggle in our particular situation. We do dip into our savings and our investments and our lines of credits to pay these things, to get the support and care that not only they need, but that they deserve. There is a great financial impact and with financial impact comes emotional impact because you are always thinking about money. You are always thinking about debt. You're always thinking about how to pay off that debt. You're always thinking about that line of credit.” (Caregiver)

Addressing caregiver financial distress is the right thing to do. While caregivers act out of love and commitment, and often find their caregiving a rewarding experience, they should not find themselves living in low-income or severe financial stress as a result.

Income is well recognized as one of the key social determinants of health.¹⁴ Chronic stress arising from financial pressures and low income has consequences for physical and mental health, whether through physiological consequences, reduced access to healthy diet or activities, or maladaptive coping behaviours. Thus, caregiver financial distress has direct implications for caregiver health and wellbeing, both immediately and in the long-term.

Financial pressures can also affect the quality of care that caregivers can provide for their loved ones, whether because they cannot afford to provide the supports and services that their loved one needs, or because the impact of financial pressures on their own health and wellbeing undermines the attention that they are able to provide to their loved ones. For example, a study of cancer patients receiving palliative care at home found that caregiver distress was associated with worsened physical symptoms for care recipients.¹⁵

It's important to underline that these consequences will fall more frequently and heavily on some groups than others. While both men and women provide care, women take on disproportionate levels of caregiving, leading to higher burdens of depression, anxiety and deteriorating well-being, as well as more significant short and long-term economic consequences.¹⁶ Newcomers and racialized caregivers often start their caregiving journey with lower incomes and fewer financial resources, so that the costs of caregiving can have especially heavy consequences. As well, the shortage of supports tailored to meet

culturally or linguistically specific needs means that these communities may have less access to the resources that they need to care for their loved ones and to balance work and care.¹⁷

Beyond these direct impacts on individuals and communities, addressing financial distress is also a practical and cost-effective step for governments. Financial distress is a significant cause of collapse of care in the community. Where the financial costs of caregiving become unsustainable, families may have no choice but to turn to institutional alternatives. Caregiver exhaustion may also lead to unnecessary admission to acute care. A Cost Benefit Analysis developed for the Ontario Caregiver Coalition found that a modest direct financial support program for caregivers of about \$400 per month could replace 7.8% of Ontario's long-term care beds. Each dollar provided in cash benefits to caregivers could replace up to \$2.69 spent subsidizing long-term care spaces. Such a transfer could immediately replace between \$479 and \$483 million in LTC beds. Gross savings could escalate over time to between \$679 and \$783 million, depending on rates of aging. This would represent a net saving of \$307 million when accounting for projected program expenses, escalating to between \$343 and \$390 million by 2040.¹⁸

WHAT CAN BE DONE TO ADDRESS CAREGIVER FINANCIAL DISTRESS?

“In the next 10 to 20 years, if there aren't supports available for the person who's ill as well as the caregiver, then I think we run into dangerous territory. From all parts - from the health care workers being overworked and under resourced and underfunded to women leaving their jobs trying to be the caregiver - and in most cases it's women caregivers, women out of the workforce – [...] turnover for employers because they're trying to fill spots and people are leaving. I think there's a big implication and a big effect to what we are going through.” (Caregiver)

There are a number of policy avenues to address caregiver financial distress

1. *Provide caregivers with direct financial supports through effectively designed tax credits or caregiver allowances:* Direct financial supports to caregivers can be an effective policy option by enabling caregivers to offset the costs of caregiving, in this way creating both more support and more flexibility for caregivers. Such supports provide a signal to caregivers that their efforts are recognized and valued. Models for direct financial supports already exist in Nova Scotia, Manitoba, and Quebec. Ontario can learn from best practices in those jurisdictions to make implementation easier and more effective. As the Cost-Benefit Analysis developed for the Ontario Caregiver Coalition demonstrates, direct financial supports, by making care easier to sustain, can reduce dependence on expensive institutional approaches and directly save the government money.

EXAMPLES OF DIRECT FINANCIAL SUPPORTS FOR CAREGIVERS

Nova Scotia: The Caregiver Benefit program provides an allowance of \$400 per month to caregivers who are in an ongoing care relationship with the person receiving care and who provide 20 or more hours of assistance per week. This is an income tested program.

Manitoba: The Primary Caregiver Tax Credit is a \$1 400 refundable tax credit per year to a person providing unpaid care to a family member, friend or neighbor who has been assessed as requiring significant levels of assistance.

Quebec: As part of its ambitious and comprehensive Caregiver Strategy, Quebec provides a suite of tax credits. This includes a tax credit for the cost of specialized respite services, a refundable tax credit for those caring for a person over the age of 70, and a separate refundable tax credit for those caring for persons living with a disability.

2. *Strengthen Home and Community Care supports:* The current crisis in Ontario's home and community care system has been widely acknowledged. While in recent years Ontario governments have made investments in home and community care, more is needed. This includes implementing an effective health human resources strategy that includes wage parity across the health care sector. A home-first strategy can support caregivers, provide care recipients with the future in the community that almost all hope for, and reduce costs to the health and social services systems.¹⁹
3. *Strengthen supports and accommodations to enable caregivers to sustain both employment and caregiving.* This can include strengthening the employment standards and human rights protections for employees who are juggling caregiving and employment. For example, the Ontario Human Rights Code provides some rights to accommodation for caregivers based on family or marital status. However, these rights are limited in scope and frequently poorly understood by both employers and employees.²⁰ The Ontario Human Rights Commission has suggested that strengthening access to health and retirement benefits for part-time workers and workers on leaves of absence could be important for addressing the needs of those with caregiving responsibilities.²¹
4. *In concert with improved Home and Community care supports, broaden access to self-directed funding programs that allow families to purchase the services they need most from the providers of their choice.* Ontario's self-directed funding programs include its Passport, Special Services at Home, Family Managed Care and Self Managed Attendant Services programs. Research finds that while not appropriate for all families, where there is a fit, self-directed funding programs can lead to greater care continuity, fewer unmet needs, innovative use of public resources, and higher overall user satisfaction compared to traditional home care services. Caregivers emphasize the benefits of choice and flexibility in developing creative solutions to meet

unique family needs and developing trusted and stable care-providing arrangements. Because families can directly select supports, they have greater flexibility to ensure that care is delivered in accordance with cultural needs and in the language of the care recipient. Broadening access to these programs can ensure that those families who can benefit have the choice to do so. However, Ontario's families often have difficulty accessing its Self-Directed Funding programs. Barriers include eligibility requirements that tend to exclude significant groups of potential users, administrative set-ups that require families to pay costs up-front and wait for reimbursement, and long waitlists and limited funding envelopes.²²

The most effective response to caregiver financial distress lies not in selecting one of these options, but in a comprehensive approach that would **prevent** financial distress by strengthening access to health and social services, **reduce the impact** of caregiving on labour force participation, and **support caregivers** directly through allowances or tax credits.

CONCLUSION

It is common for caregivers to experience financial distress as a result of their caregiving role, whether because of out-of-pocket expenses, or the impact of caregiving on employment. Caregiver financial distress has significant impacts not only on caregivers, but also on care recipients and on our health and social services systems. As of yet, policy-makers have not turned their attention to this issue in a systematic or meaningful way. Addressing caregiver financial distress requires a comprehensive response that would support caregiver participation in the labour force, strengthen access to health and social services and provide caregivers with direct financial supports.

ENDNOTES

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